Dementia and how to deal with it

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Introduction

This practical guide is first and foremost for people who have dementia (Alzheimer's and other forms of dementia – see the first chapter) and those who care for them, but it also provides useful information for anyone who would like to be better informed about the illness. The guide sets out questions and answers so as to provide simple, useful information in function of your needs (1).

Perhaps you have just learned that you yourself or one of your family has dementia, or another type of neurodegenerative disorder that is incurable at present. The shock of learning such a thing is always considerable and after such a diagnosis, we immediately think that nothing will ever be the same again.

However, everything does not change from one day to another. Life does go on and, in the interests of everyone concerned, it must continue to do so for as long and as normally as possible. Although dementia cannot yet be prevented or cured, a great deal of progress has been made regarding its diagnosis, treatment and management. We often have in our mind's eye extreme images that correspond to the terminal phase of memory diseases, but before getting to this stage, there is generally a rather slow evolution. For the person with dementia, moments of memory loss usually alternate for a long time with periods of perfect lucidity.

Understanding the illness, knowing more about existing medicines, the support services available, the institutions and activities that are specially suitable for dementia, and even the legal assistance at your disposal, are just some of the many options that can enable you to make fully-informed choices and help you to manage dementia.

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(1) Research shows that among multilingual people with dementia, the mother tongue is likely to be the last to be affected by dementia. If you have dementia and your first language is French or Dutch, we suggest that you download or obtain this brochure in your mother tongue:

In French: https://media.kbs-frb.be/fr/media/8229/2021_PUB_3816_FR_Alzheimer

In Dutch: https://media.kbs-frb.be/nl/media/8641/PUB_3815_NL_Dementie

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1. DEMENTIA: WHAT DO WE KNOW ABOUT IT?

DIFFERENT NAMES

In everyday life, people often talk about 'Alzheimer's disease' when referring to any form of progressive and irreversible deterioration of memory and cognitive function. This is particularly the case for French speakers, for whom the term 'démence' is often associated with the idea of madness. Madness, however, affects a person's spirit and reason, but does not necessarily imply brain damage. Alzheimer's is also frequently employed for the names of associations and support groups working in this field (e.g. Alzheimer Belgique, Ligue Alzheimer, Alzheimer Liga Vlaanderen).

However, throughout this brochure, we shall use the correct English term 'dementia'. This is an umbrella term used to cover a range of similar neurological conditions. The most common form of dementia is Alzheimer's disease. Alzheimer's is caused by an accumulation of toxic protein fragments in the brain which cause a progressive and irreversible loss of nerve cells.

The second most important type of dementia is vascular dementia. This is caused by a reduced blood supply to the brain, which damages and eventually destroys brain cells. Then, there is frontotemporal dementia (a group of illnesses characterised by behavioural and language problems), Lewy body dementia or LBD (caused by the presence of protein deposits in the brain) and Huntington's disease (caused by a defective gene that leads to the brain becoming damaged over time).

Dementia is therefore not one specific illness with one particular cause. Instead, dementia describes a range of symptoms caused by disorders that affect the brain. As it develops, dementia affects thinking, memory and the ability to perform everyday tasks.

WHAT DO WE KNOW ABOUT DEMENTIA?

Dementia is a neurodegenerative disorder. It comes about as the result of a progressive and irreversible loss of nerve cells or neurones in the brain, which are the support of our mental faculties. How it develops and the duration of the illness varies from person to person, but there is a typical pattern. There is a **gradual and irreversible loss of brain cells or neurons in the brain**. This affects our mental capabilities and our skills.

In the case of Alzheimer's disease, two phenomena happen simultaneously in the brain of the person affected: firstly, the formation of senile plaques between the nerve cells, the main component of which is a protein (beta-amyloid). There is also the appearance inside the neurons of fibrous tangles (or lesions of neurofibrillary degeneration), which consist mainly of deposits of another protein called Tau, which is normally part of the structure of nerve fibres, but in this case can no longer carry out its function.

The origin and precise cause(s) of dementia are still not fully understood. Contrary to received opinion, the hereditary forms of dementia are very rare (and amount to only a few families in Belgium). Dementia is, however, an illness that can affect anyone, in any case after the age of fifty (it very rarely affects young people), but it is an illness that above all affects the elderly. Nevertheless, given the general increase in life expectancy, it is logical that more and more of us are faced with developing dementia.

The seven greatest influences associated with the risk of developing dementia are: too little mental stimulation (in work, hobbies or social activities), smoking, too little physical exercise, depression, high blood pressure (from middle age), diabetes and overweight (from middle age).

HOW DEMENTIA DEVELOPS

There are many manifestations of dementia and **no doctor can predict with certainty the evolution of your state of health if you have this illness**. It may be faster or slower and the illnesses will present highs and lows, with some days, or even periods, that are better than others. People with dementia live on average for eight years with the illness.

At the start of the illness, you can behave almost completely normally in your everyday life, with your intellectual faculties largely preserved, and you can live independently.

However, the loss of nerve cells ends up by creating a certain number of **difficulties**.

- The illness causes memory problems. For instance, recent events and appointments are forgotten.
- Research shows that in multilingual people with dementia, the mother tongue is likely to be the last to be affected by dementia.
- Communicating with other people becomes more difficult. Understanding and making oneself understood can no longer be taken for granted.
- Planning and carrying out new or complex tasks poses problems. On the other hand, you will no doubt continue to do well the things you do regularly.
- New or unusual situations can be confusing. You risk, for instance, experiencing greater difficulty in navigating around places that you don't know so well.

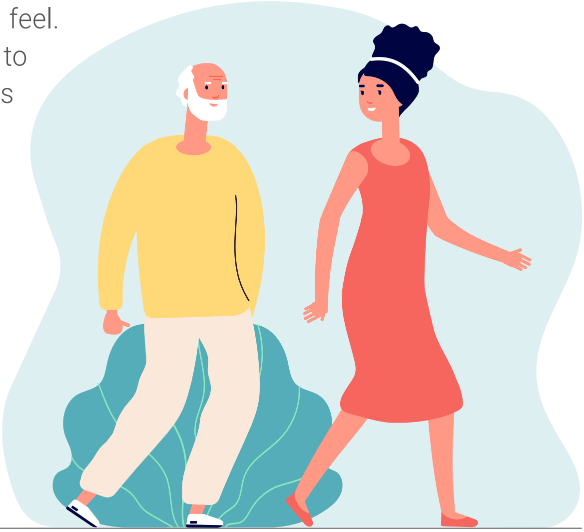
- Your moods become more changeable. Emotions, frustrations, feelings of fear or sadness may suddenly come over you for no apparent reason. Your personality and behaviour may change. In Lewy body dementia, such changes may be sudden and violent.

Most patients experience periods of total clarity but also moments of mental confusion. The latter come every now and then in the beginning, but later appear more frequently.

WHEN SHOULD WE BEGIN TO WORRY?

Your memory suddenly lets you down, you experience things such as confusion, distraction or bouts of fatigue. There's nothing exceptional about this, especially from a certain age. It's not because you can't immediately remember the name of a friend that you are already "becoming an Alzheimer's case" as people say jokingly.

However, it is the abnormal repetition of memory loss problems and, above all, the combination of this with some of the other symptoms described above, that should alert you to discuss how you feel. You should not hesitate to discuss this with members of your family or friends, to see if they have noticed the same things as you.



If you, or someone you know feel really worried about memory loss, if you have the impression that you can no longer remember really important things, if you experience frequent mood swings and increasingly experience problems of concentration, especially when doing new things, the best thing is to speak to your family doctor. He or she may send you to see a specialist (a neurologist or geriatrician) and a neuropsychologist in order to establish a diagnosis. The specialist will prescribe a number of tests, such as an MRI (magnetic resonance imaging), or conduct analyses such as a blood test. The neuropsychologist will ask you to complete a number of cognitive tests. This may all seem rather a lot and some of the questions may even seem a bit stupid, but all of the tests are designed to provide the best possible evaluation of the state of your memory.

In some hospitals, there are also memory clinics, where the teams have at their disposal a wide range of investigative methods, including cognitive tests, blood tests, an analysis of the cerebrospinal fluid (obtained by lumbar puncture), a brain scan (a scanner measures the brain's metabolism) and magnetic resonance scanning.

Today, there is an abundance of information at our disposal for us to consult ourselves. However, **do resist the temptation to make your own self-diagnosis!** Arriving at the right conclusions demands experience and a body of evidence drawn from several sources. In other words, even the most serious Internet website cannot give you the diagnosis you need. You may even be misled, leading you to confuse neurodegenerative conditions with other problems such as depression or burn-out and delaying the moment when you go and see a doctor.

HOW TO DEAL WITH THE DIAGNOSIS OF DEMENTIA?

After having completed all the tests with a specialist, you may have the nice surprise of learning that you are not ill after all. If there is a problem, however, it is helpful to know what to expect. And once the situation has been made clear, you will then have the tools to deal with it.

Of course, we have to look things in the face: at the moment when the diagnosis is delivered, it is often really painful. It is a moment when our most overwhelming emotions – turmoil, anger, sadness, revulsion, shame – jostle around in our head. This is why you should not face this situation alone. When you go for the diagnosis, ask someone to go with you.

Sometimes, the fact of being able to put words to describe the problems that have been worrying you for a while are a relief and this may even free you from a feeling of guilt. A diagnosis will help you and those dear to you to better understand some of your unusual reactions or behaviour.

The earlier a diagnosis is made, the easier it is for you to organise your life in relative calm. Once the first moments of shock are over, you will have the opportunity to make, step-by-step, a series of decisions about your health, organising your daily life or managing your inheritance. And you can do this by adapting your lifestyle, calling upon support services and giving appropriate instructions to those who are close to you.

In short, by facing up to reality, you can remain the main actor in your life and have the support and involvement of those close to you.

You should not get alarmed at the slightest memory problems. However, if you notice an accumulation of symptoms, with difficulties of concentration, knowing where you are in time or space, or adapting to even the slightest new thing, then please see your doctor or go to a specialised centre. They alone can establish a reliable diagnosis.

WILL I LOSE CONTROL OF MY LIFE?

After a diagnosis of dementia, how you live your life will change. But you will not find yourself living in another dimension from one day to another. You will, no doubt, have long years ahead of you, during which you can carry on doing lots of activities, interact with those around you and make new discoveries.

> Just like aging or losing some of your physical strength, dementia will lead you to drawing a line over a certain aptitudes, skills and habits. However, you will still have many capacities and numerous happy moments to enjoy and share with those you hold dear. Life does not come to a standstill on the day you learn that you have dementia.

If you have grandchildren, even of a very young age, do not think that you are ‘protecting’ them by keeping them away from the situation. Explain to them what is happening to you, perhaps with the help of books about dementia that have been specially written for them and which will help them to understand the situation. The authenticity and spontaneity of their reactions will surprise you!

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The best way of dealing with this illness is to speak about it openly, frankly expressing how you feel about it.

2. WHAT TREATMENTS ARE AVAILABLE? WHICH HEALTH PROFESSIONALS CAN BE OF HELP?

WHAT TREATMENTS ARE AVAILABLE?

Despite the progress in medical knowledge, there is still no medicine or treatment to cure dementia. The only way to slow down or avoid dementia is to fight against a series of factors that are known to ‘weaken’ our brain cells and induce dementia-type lesions. These factors include repeated cranial trauma, vascular problems (arterial hypertension, high levels of cholesterol, diabetes and heart disease) and harmful lifestyle habits such as excessive alcohol or tobacco consumption. On the other hand, professional and social undertakings, as well as intellectual activities (such as board games) and physical activities (such as walking and dancing), appear to play a protective role.

There are some medicines that act on symptoms of the illness, such as memory loss, language problems, reasoning and motor problems, by diminishing their severity and slowing down the development of the dementia. Such symptomatic treatments can improve your quality of life over many years. It should, however, be noted that the efficacity of these medicines varies from one person to another and indeed may have no effect at all in some patients. The secondary effects experienced when taking these medicines may also be very different.

There are two kinds of treatments:

- **Cholinesterase inhibitors (ChE)** block the action of cholinesterase, an enzyme that destroys a neurotransmitter in the brain called acetylcholine. This neurotransmitter is involved in attention and, indirectly, in memorization and learning. The more its level falls, the less well the brain acts. In a person with dementia, a ChE inhibitor can contribute to stabilising the person's cognitive functions. Several medicines of this type exist, administered either orally or as a patch.

- **Memantine hydrochloride** acts on another neurotransmitter: glutamate. The brain needs glutamate for memory and learning, but in dementia, the neurons release too much of it. The excess glutamate fixes itself onto the receptors of other nerve cells, which it then overstimulates, to the point that they no longer recognise normal signals of information. As a result, the brain functions are in freefall. Treatment with memantine slows down this process.

It is your doctor who will decide whether, in your case, a double therapy combining both of these treatments should be envisaged. Since the medicines for dementia are relatively expensive (even though cheaper generic forms now exist), they are only reimbursed, in agreement with your doctor or health insurance, if their efficacy on you has been noted in an evaluation made every six months by the specialist. Once the illness is very advanced, the efficacy of the treatment diminishes and so reimbursement is no longer possible.

Other medicines, such as sleeping tablets, anti-depressants and anxiolytics, help to treat the symptoms of sleeplessness, anxiety and a tendency to depression, which often follow presentation of the diagnosis.

WHICH DOCTORS CAN HELP ME?

General practitioners are the health professionals most suitable to support you, especially if your GP has been your doctor for a long time. You can talk to them about your physical problems, but you can also discuss with them your morale or other difficulties, such as relationships, that you may be encountering in everyday life. Since they know you well, they can calmly evaluate your problems and, if necessary, re-direct you to a specialist. If required, they can also get in direct contact with this specialist and explain to you his/her observations regarding certain issues that may seem a bit complicated to you. Try to have a family doctor who is relatively available and with whom you feel at ease in discussions. Like any good family doctor, he/she will also ensure the monitoring of your general health, looking out for things such as hypertension, diabetes, rheumatism and sight or hearing problems.

It should be noted that, even if your doctor sometimes comes into contact with members of your family, he/she is not allowed to infringe medical secrecy and discuss your health with them unless you have given your authorization to do so. If you are concerned by this aspect, do not hesitate to discuss it with your doctor.

As far as specialist doctors are concerned, neurologists are well-informed about dementia. They may also prescribe any necessary medicines and monitor the evolution of your illness. You will generally consult a specialist firstly for a diagnosis. Then, a few months later, you will return to the specialist to see the effect of any medicines you have been prescribed. And after that, six-monthly visits are recommended.

Psychiatrists will help you if you experience great anxiety or depression (if, for instance, you have the on-going feeling that you can't enjoy life or that it's not worth living any more), or insomnia etc. If necessary, the psychiatrist will prescribe a medicine to help you, but he/she will especially encourage you to talk about your feelings, both to them and to your family and friends.

Geriatricians are specialised in the physical, mental and social disorders of the elderly. You should not hesitate to consult a geriatrician as soon as the first signs of the illness appear. Thanks to their comprehensive and multidisciplinary approach to problems, geriatricians can guide you with great insight at the moment of diagnosis, programme regular follow-up appointments and foresee, together with you, your family carers and others, the preventative and progressive measures that are likely to slow down your functional decline. These specialists are mainly found in the geriatric departments of hospitals.

You can also get support from other health professionals:

Neuropsychologists are not doctors but, like psychologists, they are specialised in neurological problems. After you have completed the relevant tests to establish a diagnosis, neuropsychologists are able to make an evaluation of your cognitive faculties on a regular basis. They can also give you advice on how best to use your capacities.

Psychologists and other psychotherapists can provide you with support if you feel the need to talk about your personal or relationship difficulties with someone who is a neutral, external actor.

Physiotherapists, who exert a paramedical profession, can help in slowing down the degradation of movement, through exercise and massage. They can also alleviate some pain, notably that due to blockage of the joints.

Occupational therapists can help you to retain optimal functioning in your personal life of physical and social activities. They study your environment and suggest modifications so as to make your home as well-adapted as possible and make your daily life more pleasant and comfortable.

Speech therapists can help you and your family to develop strategies to compensate for memory loss when you talk.

Research shows that in multilingual people with dementia, it is usually the mother tongue that remains for the longest time. So, if you are multilingual, it is a good idea for you, your carer and your health professionals to use your mother tongue if possible.

It should be noted that the services of some of the professionals mentioned above are not reimbursed by your (health insurance) mutuelle / mutualiteit.

WHAT ROLE CAN COMPLEMENTARY MEDICINES PLAY?

Complementary medicine covers a vast array of therapies and medical practices. The best known are homeopathy, herbal medicines, aromatherapy, naturopathy, osteopathy, chiropractic and acupuncture. However, the real efficacy of these numerous non-traditional therapies is not, or is insufficiently, proven, at least according to the criteria of evidence-based medicine.

Moreover, it should be remembered that ‘natural’ is not synonymous with ‘inoffensive’. Thus, medicinal plants, and in particular essential oils, may modify the effects of classic (allopathic) medicines that you have been prescribed. You should therefore get information about any possible interaction with traditional medicines. In fact, as a general rule, if you decide to use any complementary medicines, you should inform your doctor and pharmacist about this.

It is important to stay in touch with health professionals so as to know about all of the treatment possibilities, discuss any secondary effects and ask any other questions you may have. This will also enable you to be sure the treatment you are being given is effective and appropriate for you or the person you look after.

There is currently no curative treatment for dementia. However, certain medicines can slow down the progression of symptoms and various health professionals among those mentioned above can provide you with specialised help and support.

3. HOW BEST TO ORGANISE MY LIFE AT HOME?

Gradually, your life will change. You will perhaps need care, support or assistance for certain tasks that risk becoming too difficult. Even if the members of your household are willing to help you, they must not take on too much, running the risk that their care becomes a crisis.

THE CARER, A CRUCIAL ROLE

It is much better to have someone close to you, who stays by your side in a well-defined role than having someone who wants to do too much and ends up being exhausted after a certain time.

The diagnosis of dementia also has an effect on the patient's entourage, on 'family carers'. Just like you, those who share your life need time to understand your illness and come to terms with the new situation. In addition to being worried about you, they too can feel bewildered and powerless.

Family carers have a hugely important role to play in our healthcare system. Thanks to the laws of 12 May 2014 and 17 May 2019 regarding 'recognition of the family carer helping a person in a situation of great dependency', family carers now benefit from official recognition and a legal status. The legislation permits, for instance, to combine career and holidays. However, this status is not yet accompanied either by specific social rights or financial aid.

Various brochures have been written for family and other carers and we warmly recommend you to read them. Help and information for carers can also be found at patients' associations and especially at the asbl Aidant proches or Steunpunt Mantelzorg vzw, which are specifically dedicated to them, and also at Alzheimer Liga Vlaanderen and Alzheimer Belgique.

However good your relationship with your family carer(s), a carer is in a difficult position. He or she also needs support and above all needs proper 'respite measures' him/herself (1). Encourage your family members to take some time to relax, to have a social life, do leisure activities, regularly take a few days' rest to unwind and recharge their battery. Without this, your carer will sooner or later run the risk having a breakdown themselves. And then you would suffer as much as them.

You will certainly not immediately need all the services mentioned in this section of the brochure. However, do not wait until you find yourself in an urgent situation to contact them. Ideally, setting up these different networks is something that should happen bit by bit, in function of your needs and in as calm a situation as possible.

Carers are obviously extremely precious, but they can also generate conflicts if their roles are not clearly defined from the beginning. Not only would you perhaps have the disagreeable impression that your home is being invaded, but some of the helpers might risk 'treading on each other's toes' or, on the contrary, risk neglecting certain tasks, believing that it is the other carer's job to do it. So do take care to define each person's role and function and, where necessary, do not hesitate to write down some instructions for them.

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(1) In its 2014 report 'Mesures de soutien aux aidants proches – Une analyse exploratoire (Support Measures for Family Carers – An Exploratory Analysis), the Centre Fédéral d'Expertise des Soins de Santé KCE underlined the importance of such 'respite measures', which enable family carers to have a break and temporarily give up their care responsibilities. The report can be downloaded from the KCE website: https://kce.fgov.be/en in the section Rapports KCE > Publications.

WHERE TO GET INFORMATION

As we have already mentioned, the first port of call for advice is your **family doctor**.

Several well-organised **associations** and centres are specialised in dementia *(see the list at the end of the brochure)*. They themselves offer numerous services and can also inform you about everything else that exists in your neighbourhood or commune.

The **communes** (your local authority) also know about the available services in your area. Find out more by contacting the people responsible for social affairs, the family, or the elderly at the town hall.

Contrary to popular belief, the CPAS/OCMW (Belgian social services) are not limited to providing services only for vulnerable people. They also offer a range of services for those with dementia. The CPAS/OCMW of your commune may, for instance help you with the payment of your invoices or your administrative documents (an administrator can also perform this role – see later).

You should also ask about help and support from your **health insurance** (mutuelle/mutualiteit).

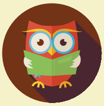
HOME SUPPORT SERVICES

It is possible for you to request a **nurse or a home care nurse** to visit you at home to undertake bathing and personal hygiene care, as well as minor medical tasks (e.g. changing plasters, injections, drips etc). You can also ask for a home help to do the housework, shopping, preparation of meals, washing, ironing and other daily household tasks.

These various services are coordinated by **care and home help centres**. These also offer the services of day and night home nurses, social assistance, telemonitoring, speech therapists, physiotherapists, hairdressers, dentists etc. They begin by making an evaluation of your needs together with you and/or your family. You can obtain the services of a qualified home help by contacting various local agencies such as ALE *(Agences Locales pour l'Emploi)* in French-speaking regions and *'diensten voor huishoudelijke hulp'* in Flemish regions, or to an authorised services voucher company (*Titres-Services* in French and *Wijk-werkcheques* in Dutch). There are also privately-run organisations providing support.

You should be aware that, despite their skills and willingness, the people mentioned above do not necessarily know about the specific difficulties associated with your illness. Moreover, there is a high level of staff rotation: no-one is available 24 hours a day, so you will often be dealing with different people.

There are also volunteers who have been trained to keep people with dementia company.



Do not hesitate to call upon these support services, but do remember to define each person's roles. It is your and your family's responsibility to do this.

HOW MUCH DOES IT COST?

① In principle, nursing care is free if you have a medical prescription. Nurses recognised by the RIZIV/INAMI (the National Institute for Health and Disability Insurance) offer the same services and at the same rates whether they are employees or self-employed. Your health insurance fund (mutuelle/mutualiteit) pays all or part of the cost. However, some self-employed nursing services that do not have RIZIV/INAMI status may sometimes request a supplement.

② Across Belgium, the cost of a carer is hourly-based and depends on the income of the beneficiary and his/her family situation. In-home care is relatively costly and prices can vary quite a lot, including by region.

In French-speaking areas, the cost of home care is established by the social worker, based on an official scale established by the COCOF in Brussels and by the Walloon Region for Wallonia. In the Walloon Region, the cost of an hour's work for a carer varies between € 0.87 and € 7.8, and in the Brussels-Capital Region, it is between € 0.59 and € 6.19.

③ There is a separate care insurance scheme covering Flanders and Dutch speakers in Brussels, which provides partial funding for non-medical help and home care or residential care services. People with serious care needs – serious long-term impairment of their ability to care for themselves – are eligible for this. Residents in an approved institution automatically receive this care premium, based on a certificate of residence. People living at home, on the other hand, can apply for the premium by submitting a medical certificate. It should be mentioned that not enough people are aware of this system, even though everyone in Flanders has to be registered with an approved care fund and pay an annual contribution to this from the age of 26. In the Brussels-Capital Region, membership of the fund is optional. The care funds are set up by the health insurance organisations (mutualiteit) and by insurance companies, so an application to receive the premium should be made to whichever you use.

④ From the age of 65, you can also benefit from an allocation of 'aid for the elderly' (APA - Aide aux Personnes Agées in French, and THAB – tegemoetkoming voor hulp aan bejaarden in Dutch). This is a complement to the retirement pension or survivor's benefits or the Guarantee of income for the Elderly (GRAPA). The allocation is calculated in function of the observed seriousness of lack of autonomy, of your family situation, your income and that of your partner.

⑤ **If you live in Wallonia**, to introduce an APA request you can apply to your (health insurance) mutuelle, your local commune, or to the CPAS/OCMW of your commune. You can also apply directly to the Walloon social security platform 'Wal-protect' (www.wal-protect.be). Access to this platform is via your identity card using an eID card reader or by itsme®. It is your mutuelle which (under control of the AVIQ, Agence pour une Vie de Qualité, www.aviq.be) deals with the medical recognition of your disability for your APA request.

If you live in Wallonia, to introduce a THAB request you can apply to your (health insurance) mutualiteit.

If you live in Brussels, to introduce an APA/THAB request, you can contact Iriscare, either by filling in the form online at www.myiriscare.brussels, or by requesting a paper version to complete by telephone *(0800 35 499, from 8h to 16h30, except Monday afternoon)*, by e-mail *(apa-thab@iriscare.brussels)* or you can apply by post to Rue de Trêves 70, Box 2, 1000 Brussels.

A care package for seriously ill people (officially called ‘forfait malade chronique’ in French and ‘forfait voor chronisch zieken’ in Dutch) can also be obtained at any age, under certain conditions. Information about this is available (in French and Dutch) on the website of the National Institute for Health and Disability: www.rizi.fgov.be or from your health insurance organisation.

⑥ Some hospital insurance contracts cover care related to dementia. You should check this out with your health insurance (mutuelle/mutualiteit) and/or your insurance company.

LEISURE AND RECREATION

It is important, as much as possible, that you continue to do the activities you did before you learned of your diagnosis. Whether you are a member of a walking club, a member of your local neighbourhood committee, played cards every weekend or whatever, please don’t change your habits! And don’t be afraid to openly talk about your illness. Your friends will appreciate your honesty. They will be able to take account of your difficulties by speaking a little more slowly, for instance.

There are many other ways to relax, have fun, get away from your worries, reassess yourself, or develop other forms of expression: for instance through drama, dance, yoga, rhythm, singing, conversation, storytelling, music and art therapy, touch therapy or aromatherapy. And these are just a few of the options. You will no doubt be a little less efficient in some activities, but there is certainly no lack of options!

If you would like to meet people who are experiencing the same thing as you are, you could also contact one of the associations that exist for patients with dementia and their families.

HOW TO ORGANISE YOUR DAILY LIFE

If you suffer from memory problems, there are several strategies that can be of help. These little things may seem insignificant, but they will facilitate your life in certain circumstances.

- **Use a diary** in which you can note important information and keep it with you at all times. Write down your most important phone numbers, (including your own!), a list of things you have to do, your appointments etc. Attach a map of your neighbourhood, with your home marked on it.

- Follow a daily and weekly **routine**. This will help you to keep your bearings.

- **Simplify your household**. Put away things that clutter up your space. Get rid of the things that you no longer use.

- Use a **big calendar**, which enables you to see which day it is, and note down on it your appointments or other information.

- Get a **big clock**, with a clock face that clearly shows the hours, date and day of the week.

- Put **labels** on your drawers and cupboards, using words or pictures that indicate the content. Prepare little reminders that indicate, for instance, the way to the bathroom or cellar.

- Gather together the **photos of people you see regularly**. Note on each photo the name of the person, what he/she does and what bonds you to that person.

- Get a **simple mobile phone** so that you always have with you the most important phone numbers.

- Get hold of **a 7-day pill organiser** (a box with a compartment for each day's pills) that will help you to remember when to take your pills.

- **Program** your mobile phone to remind you to take your medicines for instance, or when to go to important appointments or meetings.

- Swap your gas cooker for hotplates that have a safety device. Get your boiler or water heater adjusted to have an average temperature so that there is no risk of getting burned.

- Ask your family to help you organise your clothes wardrobe and drawers to make your choice of clothes easier.

ESTABLISH SOME ATTAINABLE GOALS FOR YOURSELF

Over time, you will no doubt notice that you are no longer able to accomplish certain acts or tasks, things that had previously presented no problem. Such a realization can obviously be a little disheartening, but in the end, this is something that we all face as we get older. For you, this is simply a process that is happening somewhat earlier and a little differently.

Do not feel guilty about this and do not persist in trying to do things that are too difficult. Instead, try to establish **some new objectives that are realistic and achievable**. Focus on what gives you pleasure. Allow yourself to stop and take a rest when you need to. And, occasionally, do not hesitate to try out something new.

Make your life easy by adopting some new habits and establish achievable objectives. Pay attention to what you eat and your physical activities. Don't become withdrawn.

Try to keep up a minimum of physical activity, such as taking a daily walk for half an hour. This will enable you to sleep better, have a better appetite, greater strength and balance. Pay special attention to your food: continue to eat as healthily as possible.

KEEP UP YOUR SOCIAL LIFE

Do not cut yourself off from your friends and your usual activities as soon as you get your diagnosis! A rich and varied social life is one of our best defences against dementia. Keep it up as long as possible and do not be afraid of talking about your situation with the people you see regularly.

When one has dementia, it is quite normal to feel ill-at-ease from time to time. You may feel a bit embarrassed when you are with other people. However, you must not give in to the temptation to shut yourself away or withdraw into yourself. On the contrary, it is essential to carry on communicating, asking for - and accepting - help. You can still give and receive love, enjoy the little things in life, be moved by the affection shown by your family. You may even find yourself able to express your feelings more intensely and more easily than before.

At each stage of the illness, make every effort to stay in contact with other people as much as possible. Do not hesitate to join a support or self-help group organized by patient associations. These groups offer numerous activities including art therapy, walks, psychomotor education and convivial entertainment. Some of them organise group therapy, in the form of an Alzheimer's café, or reminiscence workshops conducted in smaller groups.

These self-help groups are often characterised by great solidarity. They enable you to stay informed, ask questions and to share advice and experience. You feel listened to and understood by people who have the same difficulties as you (or their families).

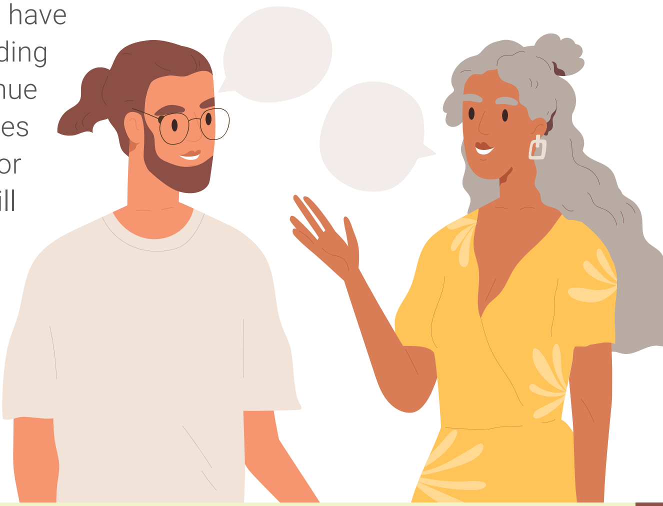
Another way of staying in contact with people is to make yourself useful, by helping with the children, for instance. Despite your difficulties, you still have so much knowledge and lots of skills to share.

And finally, don't forget that humour is an excellent way of overcoming some situations! Try to use your humour as much as possible.

HOW TO COMMUNICATE?

Will there not come a moment when you are deprived of any way of communicating?

Perhaps. No-one can say how your illness will develop. And, in any case, human relationships are not just about verbal language. Even if you are less able to speak, you will still have other ways of communicating. Our memory of non-verbal communication, which is probably the most archaic, almost always remains intact. Even if the day comes when you have difficulty in understanding the words, you will continue to understand gestures of affection, irritation or rejection and you will interpret them correctly.



We communicate with more than just words. Whether you are a patient or a carer, don't forget about the little signs of affection – a gesture, a smile, a touch – and be sensitive to those made towards you.

SHOULD I DO MEMORY EXERCISES?

Opinion is divided on this subject. However, do not force yourself to do exercises that are too complicated and which cause you to feel incapable or even angry. The loss of memory or other capacities is not the result of a lack of willpower. In practice, however, there is nothing to stop you exercising your memory through a multitude of activities in daily life that you enjoy doing.

CAN I STILL DRIVE?

Neurological troubles can affect your capacities of judgement, concentration and memorization, your perceptions and your sense of direction. These may affect your ability to drive. You risk making more errors of judgement (of distance, obstacles and speed), and of having moments when you are distracted or have slower reflexes.

This is why, if you have dementia, the law requires you to **hand in your driving licence** within four working days after your doctor has estimated that your illness is now incompatible with safely driving an automobile, or a doctor has required you to do so. Doctors are authorised to do this.

Nevertheless, you may be authorised to continue to drive if you can prove that you possess the necessary physical and mental skills to do so. In order to do this, you must take an aptitude test in one of the provincial test centres of CARA (Centre d'aptitude à la conduit et d'adaptation des véhicules/ Centrum voor Rijgeschiktheid en Voertuigaanpassing) - the **aptitude testing** centre for driving and vehicle adaptation. The contact details for CARA can be found at the end of this brochure. If you pass this test, you can retrieve your driving licence at the commune (town hall).

Having passed the test, it may be that the authorisation to drive is linked to a number of restrictions. You may only be authorised to drive a certain type of vehicle, or within a certain radius of your home, without passengers, or only during the day or for a limited period of time. Moreover, as soon as you are informed that there has been a change in your health, you must begin the procedure again.

If you do take such a driving test, do not forget to send a copy of your modified driving licence to your insurance company. In principle, the company does not have the right to increase your insurance premium just on the basis of your having had to take a CARA test, because this could constitute a type of age- or health-related discrimination. However, if this does happen, you can contact UNIA (see 'Useful addresses' at the end of the brochure) who can intervene as mediator to find an amicable solution.

If no company is willing to insure you, after three successive refusals you can contact the Bureau de tarification du Fonds commun de Garantie automobile/ Gemeenschappelijk Motorwaarborgfonds *(see 'Useful addresses')*. After calculating an equitable premium, this organisation could oblige an insurance company to insure you at this premium, subject to a possible franchise.

WHAT IF YOU CAN NO LONGER DRIVE?

Not driving does not necessarily mean an end to your independence. Think about alternatives, such as home delivery of shopping and meals, home banking, volunteer transportation and taxis (cheques), the Belbus. These alternative solutions should not necessarily cost more than that of owning a car.

4. WHAT CARE FACILITIES ARE AVAILABLE?

Various care options exist, from in-home care and temporary carers to residential care homes that can look after you as your illness develops.

DAY CARE CENTRES

Day care centres have been developed for people who have lost part of their autonomy, but can still live in their own home. These centres enable you to spend the day outside your own home, but to return home in the middle or end of the afternoon. Sometimes, this formula can avoid, or at least retard, a person's going into residential care.

Day care centres provide a safe environment for people with health issues and they offer activities that stimulate cognitive faculties and autonomy, such as reading the newspaper, memory exercises, reminiscence workshops, as well as singing, handicrafts and preparing meals together. It's an occasion to share ideas, relax and meet other people.

Day care centres also provide an opportunity for your family to discharge some of their usual tasks such as meal preparation and managing medicines. So, when you return home, the family feels more available for your well-being and they have more time to devote to their relationship with you. The ideal thing is to look for a day care centre near to where you live and to ensure that the institution stays in regular touch with your family, so as to keep them informed about your wishes and your state of health.

Some day care centres are specialised in the care of people who are disoriented, whilst others are open to receiving everyone. In the latter instance, you may find yourself with people who are more seriously ill and you may find this rather trying.

There are also centres that organise transport from your home. The disadvantage of this service is that it often means leaving home a little earlier, so that everyone can be picked up. Sometimes transport is organised by services of the commune (the local authority) or by volunteer organisations.

CAN ANYONE GO TO THESE CENTRES?

In order to be able to attend a day care centre, a doctor (your family doctor or the centre's own doctor) has to get you to take some tests, which show that you have objectively-measured difficulties according to the so-called Katz scale.

Day care centres work on the basis of daily or sometimes hourly prices. You should check with your mutuelle/mutualiteit (health insurance) whether you can be partially reimbursed for attending the centre.

Day care centres are closed at the weekend and on public holidays.

Day care centres must not be confused with day centres, which do not always meet the specific issues associated with dementia.

Day care centres provide additional care for people who have lost part of their independence, but who can continue to live in their own home. They enable family carers in particular to take a break from some of their tasks.

NIGHT CARE

In some Flemish regions, there are projects for night care, but this is not yet the 'missing link' in care homes. More information about these can be found on **www.nachtzorg.be.**

TEMPORARY SOLUTIONS

- **Baluchon Alzheimer 'Baluchonneuses**' (female volunteers) enable your family to take a few days holiday – twice a year maximum – while you stay at home. During a period of 7 to 14 days, a person specially trained to support people with dementia brings her 'baluchon' (baggage) to live with you 24 hours a day. Obviously, you would need to have a room for her to stay in. The 'baluchonneuse' takes over your partner's (or other carer's) role in caring for you every day. Your carer will have explained beforehand, during a familiarisation day, what needs to be done each day and how your home is organised. After your own carer leaves, it is the 'baluchonneuse' who takes care of everything – your personal hygiene, going for walks, shopping, meal preparation, reading, games etc., all in respect of your usual daily rhythm. She is also required to fill in a daily diary, which serves as a report about her work, but also a record of your health. **www.baluchon-alzheimer.be**.

- **Residential care homes** offer the opportunity for short stays for those with dementia.

RESIDENTIAL CARE HOMES

Going to live in a residential care home is a decision that may be justified or even indispensable in certain instances. Just like the day care centre, the residential care home can provide you with a greater sense of security and make relationships with your family more serene, by freeing them from their everyday workload, which is sometimes rather heavy and which they are obliged to assume in addition to their own personal life and duties.

The great majority – roughly 70% - of people with dementia live in their own home during much of their illness. However, it is better to avoid finding yourself in an emergency situation by taking the time to prepare any potential future change of residence while you have the time and can do so calmly, before any emergency arises. Look for information, compare the various possibilities and do not hesitate to spend a short stay in one of the homes to see how you feel about it.

HOW TO CHOOSE A CARE HOME?

You should not confuse a nursing home with a residential care home. Some homes combine both functions, either by having different wings in the building, or by offering different types or rooms. There are specialised residential care homes for elderly people who are confused.

Residential care homes ('maison de repos et de soins' or MRS in French and 'woonzorgcentrum' in Dutch) can care for people with more serious dementia. These care homes have more nursing staff, during the day and at night, and in general they offer a wider range of activities. They also have to comply with a whole series of norms that meet the difficulties associated with the illness (such as having lifts that can accommodate wheelchairs, support bars in corridors, adapted bathing facilities, medical beds etc.). However, it is important to be well-informed about the real possibilities offered by any care home you foresee going to, because descriptions are sometimes misleading.

On the other hand, some ‘simple’ care homes are establishments that are very well-equipped to dealing with demanding care needs.

It is important that you seek advice about your choice of care home. Avoid making a spur of the moment decision on the basis of what you have seen on a website or by relying on what is said about the neighbourhood. A reputation may be undeserved or may not resist a change in management for instance. Some organisations (see the addresses at the end of the brochure) carry out regular visits to these establishments, contact the control structures responsible for overseeing care homes, or collect feedback from other users. They can therefore provide you with advice in function of your own particular situation. Do not hesitate to visit your future living quarters and check whether it has been approved as a nursing home or a residential care home.

Do check too, that this establishment offers activities that are available to everyone, irrespective of the stage of illness, and that it allows you to re-constitute a part of your universe in the room or apartment made available to you (e.g. with your photos or pictures, or a favourite chair etc.). Some homes accentuate a personalised approach that provides each person a maximum amount of autonomy.

Sometimes, you will be advised to sign up to a waiting list. But be careful! Some establishments ask you for a deposit, but they will not return the deposit if you cancel your reservation, even though this practice is strictly forbidden under the law. Find out what the situation is before signing up to anything. And also be warned that the most expensive establishments are not necessarily the best.

Find out too about what happens over the long term. Will the care that is required be continued until the end, even if your condition gets worse? Nursing/care homes and residential care homes must undertake to provide a constant quality of care, whatever your state.

A care home can provide a good solution in a certain number of cases. But do not wait until the last moment to get information and visit the homes that could meet your particular needs.

HOW MUCH DO THEY COST?

In 2021, a Belgian resident paid an average of € 1,650 per month, or € 53.70 per day, to live in an MR or MRS. However, this monthly cost varies considerably from one region to another: an average of € 1,827 in Flanders, € 1,650 in Brussels and € 1,519 in Wallonia. The cost also depends on the type of room in which the resident lives: the price of a single room (the option chosen by 8 out of every 10 residents) is, on average, 19% higher than that of a double room and 28% higher than a communal room. This price covers meals, care (by nurses and carers), room rent and cleaning and the provision and laundry of bedlinen.

To this cost must be added the costs of the person's private laundry, physiotherapy (except in the case of serious illness), doctors, phone and TV, hairdressing and pedicure. On average, these supplements can amount to as much as € 100 per month. These additional costs must be set out in the home's monthly invoice.

If your own capital (pension, interest, rent income) is insufficient to pay the home's invoice, you can contact the CPAS/OCMW. After checking what you tell them, the CPAS/OCMW will calculate their contribution, taking account of a maximal daily price (for example, the price that the residents pay in their care home) rather than the daily price actually requested by the care home of your choice. You are in theory free to choose where you live, but the CPAS/OCMW refuses to pay for a home that is too expensive. Moreover, the CPAS/OCMW may also recover all or part of their contribution from your family, notably your partner, children and children-in-law.

SMALL LIVING UNITS

Small living units, comprising a maximum of 15 people, have been created within certain establishments. These units are called ‘cantous’ in French (literally ‘hearths’) and ‘kleinschalige genormaliseerd woonvormen (KGV)’ in Dutch, and they are specifically intended for people with dementia. They bring together people who have as similar a profile as possible regarding their state of confusion and offer them a style of living that is more or less community-based (by preparing meals together for instance), whilst still respecting their individuality. The atmosphere is more familial than in a classic care home. The rooms are often grouped around a communal living space. The idea is to integrate families as much as possible into the lives of the patients.

The cost for the patient is identical to that in the more traditional types of care homes.

Once more, however, do not rely blindly on descriptions. Some places called ‘cantous’ do not meet the criteria of these living spaces, whilst others, even though they do not benefit from official recognition as such, are much closer to the real concept of the ‘cantou’ or ‘KGV’.

5. THINK ABOUT LATER: RESPECT FOR YOUR INDEPENDENCE

FACING THE FUTURE

Dementia does not transform you from one day to the next. Despite the diagnosis, you are still the same person and your values have not changed. You do not, however, see the future in the same way. How would you like things to happen? What worries you most? Have you already considered the types of treatment or care that you would like to receive in the event that you can no longer express your wishes directly? And inversely, are there any treatments or types of care that you would absolutely and specifically like to avoid? Are you worried about the management of your assets? Are you worried about potential abuse and would you like someone to help you in this respect?

Even if the evolution of dementia is difficult to foresee, it is still preferable for you, and your family, to foresee as of now the time when you may no longer be able to express your wishes or make choices – personal, legal, ethical, financial etc. – with all of the lucidity you would wish for.

A number of protective measures and legal mechanisms guarantee that your wishes will be respected.

SORT OUT YOUR INHERITANCE

Do you need to draw up a last will and testament? Writing a will is not indispensable to ensure the transmission of your assets. In the absence of a will, your heirs are defined by the law. You are advised to check with a notary if it is in your interest to write a will to pass on your assets.

A key principle in law is that, to draw up a will (and this same principle applies to making a donation during your lifetime) you must be of sound mind. In other words, you must – under sanction of annulment - be fully aware of the meaning and scope of your stated wishes and freely consent to them.

Every person being presumed to be of sound mind, in the event of any dispute, it is up to the person who contests a will's validity to provide proof of the contrary. If you wish to avoid the maximum risk of dispute, the most reliable thing is to establish an 'authentic' or 'valid' will, according to which you dictate your last wishes in front of a notary and in the presence of two witnesses or a second notary. The notary will verify that the testator is free and of sound mind, and this confers greater (legal) force on the will.

This authentic will is nevertheless not definitive. You are free to modify it later, but again this should be done in front of a notary if you wish the new version to benefit from the same guarantees.

If a will is contested, it is up to the person who contests the will to prove that the deceased person was not of sound mind at the moment of writing the will. But, to avoid risk as much as possible, it is in your own interest to draw up an authentic will in front of a notary.

You should also know that the law does not allow you to bequeath your assets to certain professionals with whom you were in contact during the illness that caused your death, notably the doctors, nurses and pharmacists, as well as those people - whether employed or volunteers - who provided care at home or in any residential (care) home.

HOW TO PROTECT MYSELF?

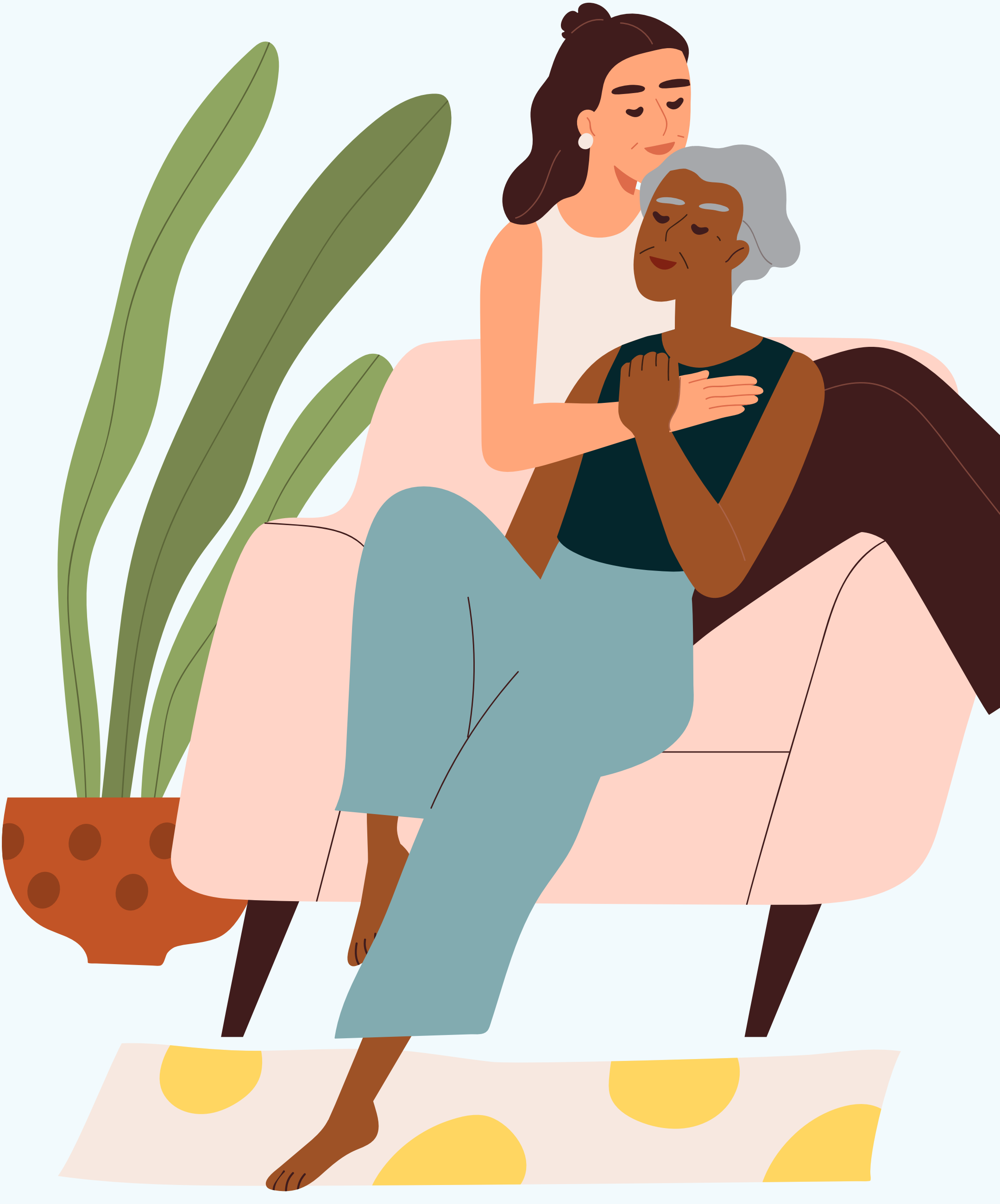
A new status of protection came into force on September 1, 2014, which replaced all previous regimes. Aimed at enabling people deemed to be 'vulnerable' to maintain the greatest possible independence, the law creates custom-made support.

VARIOUS DEGREES OF PROTECTION ARE FORESEEN

The lightest protection is that which involves a mandate being given to a third party whom you trust. If the mandate no longer protects you sufficiently, or a suitable proxy (administrator) cannot be found, a request for legal protection can be made to a justice of the peace. Initially, the administrator's mission can be limited to assistance for acts of a certain importance. The protection can, however, be easily adapted to circumstances and the justice of the peace can, where necessary, and at any moment, designate an administrator to act on your behalf and who will make decisions in your place and on your behalf. An administrator can be designated not only to manage a person's assets but also for acts that affect the person.

POWER OF ATTORNEY

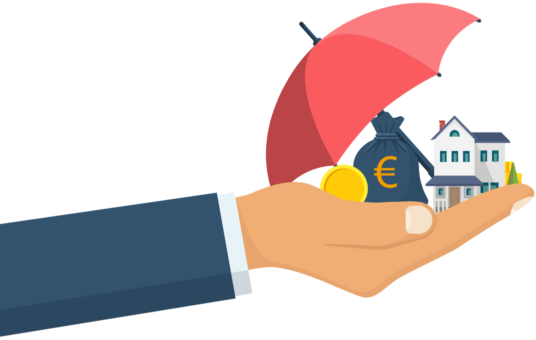
Extrajudicial protection enables you to determine yourself the manner in which your inheritance should be managed when you are no longer able to do this yourself. It is conducted by means of a **mandate**, which enables the principal – you - to give power of attorney to another person to manage all, or part, of your assets. The person should preferably be a notary. This person, the proxy, can then carry out, in your name and on your behalf, all of the things set out in the mandate, whilst you continue to do everything else. You can designate your partner, one of your children, or someone else in whom you have complete confidence to have power of attorney for you.



You maintain your capacity to conduct all acts. However, provided various formalities are respected, the power of attorney can continue even when you are no longer able to manage your assets.

LEGAL PROTECTION

Legal protection is justified when you are no longer able to defend your own interests. In this case, the justice of the peace will instigate individual support and will designate an administrator. If you are aware that you are having increasing difficulty in keeping your head above water, nothing prevents you from requesting legal protection yourself. However, this may also be requested by a member of your family or some other ‘concerned’ person, who is worried about what is happening to you (a neighbour for instance, a carer or social worker), or the Procureur du Roi/Procureur des Konings (Crown prosecutor).



This request must be made **in the form of a written application**, filed at the registry of the justice of the peace for the area of your place of residence. The application must be accompanied by a detailed medical report, dated less than 15 days’ old and describing your physical and/or mental state of health as well as proof of residence.

Do I have anything to say about the choice of administrator?

The administrator may be a member of your family or a professional. You can of course express your preferences when you appear before the justice of the peace. Naturally, this is also the case if you have designated this person beforehand in your application to the justice of the peace where you live or with the notary.

If you fear that important decisions about you might one day be taken by a third party whom you do not know or – even worse – by someone you do not like, you must take care. Your **statement of preference** (which you can change whenever you like) will be recorded in the central register managed by the Royal Federation of Belgian Notaries. And when the time comes, the justice of the peace will take account of your preferences (except of course, if this is impossible due to serious reasons, which must be clearly explained).

What exactly is the role of an administrator?

The administrator may **assist** you as a protected person, if you have retained an aptitude to understand the acts you take but for which you would like to have some help. The administrator may only intervene to give a legal opinion to an act you are undertaking, such as giving consent or signing a document, but he/she does not act in your place. If you no longer have the aptitude to understand the acts taken, then the administrator may be given a mission of representation, which means that he/she acts and decides in your place and on your behalf.

Nowadays, the justice of the peace may designate an administrator not only to manage your assets, but also for acts relating to the person. It all depends on the things you are still able to do yourself. In earlier times, a protected person was considered as being completely incapable. This is no longer the case under current legislation. Whether for the management of assets or for the person's human rights, the justice of the peace must now determine precisely which important acts the protected person is incapable of performing.

Good to know: some **combinations** are possible. For instance, the justice of the peace may choose ‘assistance’ for acts relating to the person, but ‘representation’ for those relating to managing a person’s assets.

DESIGNATING A TRUSTEE

The **trustee**, whose role is to ensure that you can lead your life as you wish to, serves as a link between you, the administrator and the justice of the peace. This person has the right to consult the administrator’s reports and supervise his/her work. The trustee’s presence is particularly useful if the judge has appointed a professional administrator who does not know you well, or not at all, but the trustee can also facilitate your dealings with a family administrator. You can designate the trustee in your statement of preference or else in a request made to the justice of the peace.

DEALING WITH BANKS AND PURCHASES

Dementia is an illness that is marked by periods of lucidity and moments of bewilderment, during which you may do things that have important financial consequences. What should you do, for instance, if you regret having made an unintended or reckless purchase?

If it is a purchase made or a contract agreed outside a point of sale (e.g. door-to-door sales, TV home shopping, telephone sales, mail order, a purchase made at a fair, exhibition or during a trip etc.) you have, just like any consumer, the right to cancel the purchase, without incurring any expense, within a certain time frame.

This right does not apply, on the other hand, to purchases made in a shop. In this case, other than starting a legal process of annulment due to absence of judgement, the only thing you can do is to request a commercial gesture on the part of the shopkeeper.

You may decide to ask your bank to fix a limit on any bank withdrawals or bank transfers that you make, in order to avoid banking operations that you might later regret. Some banks may accept to cancel transactions that have obviously been made recklessly, but this is by no means guaranteed.

Another good piece of advice: give the access codes and passwords for your bank cards and for access to your bank accounts to someone close to you. This obviously means someone in whom you have the utmost confidence.

Apart from the legal time frame that you have to cancel a ‘distance’ sale, you have very few means of recourse for any banking operation or reckless purchase. You should therefore seriously consider taking certain some preventative precautionary measures.

REFUSAL OF MEDICAL INTERVENTION

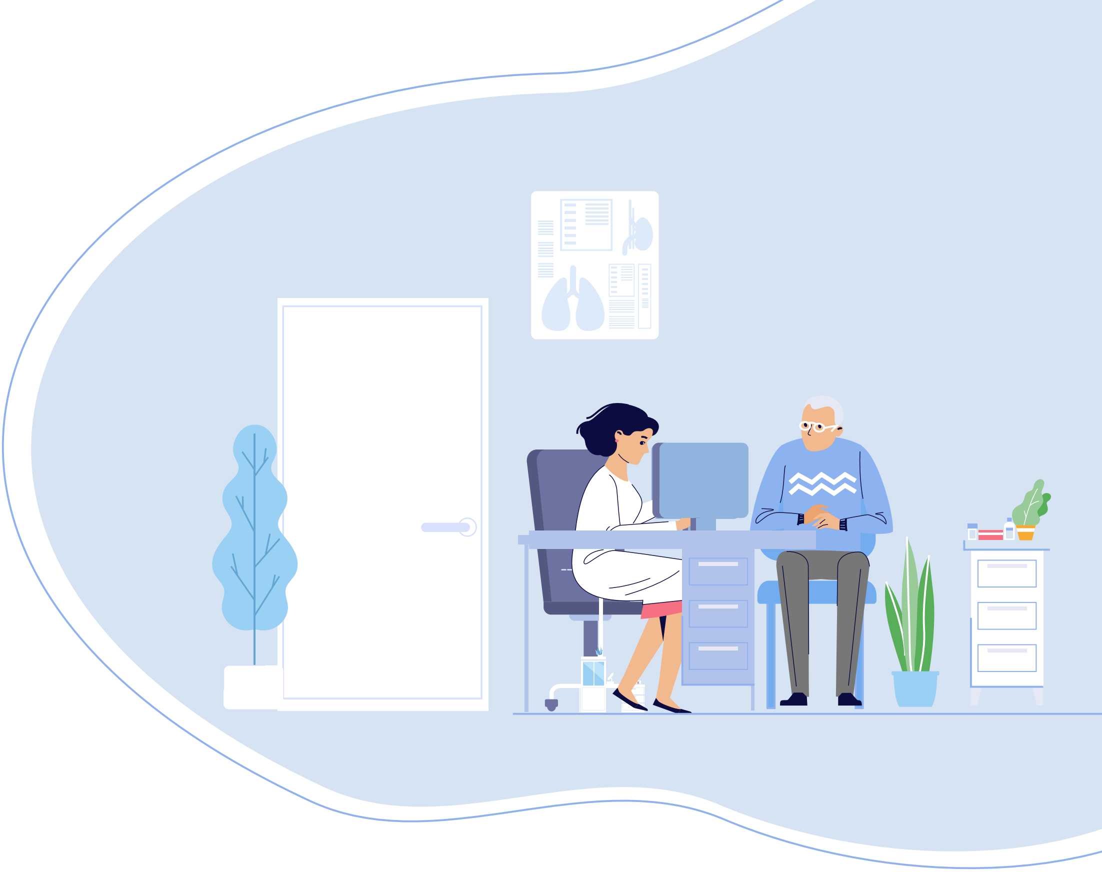
Every patient has the right, after having been correctly informed, to accept or refuse medical treatment offered by a medical practitioner. This right notably concerns acts that may be considered as a form of therapeutic prolongation of life: many people do not wish their life to be prolonged by means that they consider as artificial.

However, it may be that one day, you are no longer able to express your wishes. To avoid this possibility, you may decide to complete a 'living will' (a sort of advance declaration), or to stipulate precisely and in writing the medical intervention(s) that you refuse to have (such as resuscitation after loss of consciousness). Moreover, it is strongly recommended to designate a proxy who can show this declaration when the time comes. The doctor will then be obliged to respect your wishes. If you have not designated a proxy, your relatives may represent you and communicate your wishes to the medical staff, but the law authorises a doctor to override such a request if he/she considers that the planned medical intervention is justified in the interests of the patient.

A living will enables you, should you so wish, to avoid certain forms of therapeutic prolongation of life by indicating your refusal of a specific medical intervention. To avoid any confusion, it is in your interest to specifically designate a proxy.

You can obtain more details about this subject from Droit de Mourir dans la Dignité (ADMD) / Vereniging Recht op Waardig Sterven (RWS), an association for the right to die in dignity, as well as from palliative care associations.

Also check the links at the end of this brochure.



REQUESTING EUTHANASIA

The question of knowing whether a person with dementia can appeal to the provisions of the law on euthanasia to end his/her life has been the subject of **considerable debate**. At the present time, there are numerous people who consider that the legislation should be interpreted in a restrictive manner and that the request for euthanasia should not be envisaged in cases of dementia.

The problem comes from the fact that, if you make this request at a fairly early stage of the illness, it might be that you do not fulfil the condition, laid down by the law on euthanasia, of having 'constant and intolerable' suffering. If, on the other hand, the request is made at an advanced stage of the illness, you risk being unable to make a ‘conscious, considered and repeated request, that does not result from any outside pressure and comes from a person who is able and aware’.

Because of how dementia develops, it is effectively often impossible for the person affected to make a request for euthanasia ‘consciously and constantly’.

Can a **living will** (an anticipated declaration) clarify things? Each of us has the right to write down, at any moment, a declaration expressing our wish to be euthanised if we are no longer able to manifest our wishes. This declaration must be made by the person concerned, in the presence of two witnesses, of which at least one is not the heir to the person’s estate, nor has any material interest in his/her death. If a living will regarding euthanasia was made after 2 April 2020, this is automatically of unlimited duration (instead of a duration of 5 years), but this may at any time be revised or annulled. On the other hand, if the living will was made prior to 2 April 2020, the duration of its validity is only 5 years and it must subsequently be renewed.

In order that a doctor may carry out euthanasia, he/she must ascertain that the patient is unconscious, suffers from a serious accidental affection or illness and is in a medical situation without hope of recovery. In relation to dementia, the problem is of knowing what should be understood by ‘unconsciousness’. In principle this should mean an irreversible comatose state. However, since patients with dementia continue to react to outside stimuli, it seems that in the current state of our legislation, even a patient’s living will is insufficient to authorise euthanasia to take place.

The best thing is therefore to **discuss these questions with your family doctor** or your specialist (neurologist or geriatrician).

6. ILL-TREATMENT AND THE RISK OF ABUSE OF THE VULNERABLE

Violence against the elderly, and particularly against those suffering from mental problems, is a subject that is poorly understood and far too often taboo. However, such violence is an inescapable reality, even among the elderly themselves. The elderly often fear the risk of reprisals, of being abandoned to their own fate, or worry about provoking family conflict, so they tend to cover up violence with their silence, or at least minimize what is happening, or has happened.

Abuse is a complex and multifaceted phenomenon. It is not limited to acts of physical violence. It may take other more insidious forms, from psychological stress to serious neglect, as well as restrictions on liberty or health (the abusive prescription of medicine or, inversely, depriving someone of medicines needed). This abuse is even more difficult to detect because, in most instances, it develops within an intimate setting, resulting from the degradation of a relationship of trust between an elderly person and a carer or healthcare worker. The abuse is not always intentional. The carer, whether this is a family member or a professional carer, sometimes ends up committing abuse through exhaustion, overwork or lack of training.

This is why, except in instances of serious flagrant offences, going to the police and undertaking a legal procedure are not necessarily the best solutions. In situations where an ambiguous relationship progressively develops between an elderly person and a member of the family or the person's circle, it is recommended instead to call upon a mediator or an association for abused elderly people. These can envisage a made-to-measure solution. Sometimes, by identifying the factors that trigger these situations and creating 'breathing spaces', the relationship can be prevented from degenerating and lead to the re-establishment of a sustainable equilibrium.

The abuse of elderly people is a complex and multifaceted phenomenon, which necessitates a firm reaction, but one that is adapted to each particular situation. There are specialised associations that can advise on what is the best approach to take.

7. DEMENTIA IN YOUNGER PEOPLE

We speak about 'early' or 'younger onset' dementia when the symptoms of various forms of the illness – mainly frontotemporal dementia – are manifested before the age of 65. In Belgium, the number of people affected by early onset dementia is probably around 10,000. This is, however, a very rough estimate, because in many instances a considerable period of time passes before a correct diagnosis is made. Sometimes a wrong diagnosis is made when the real problem is stress, depression, burnout or a relationship problem. According to the Alzheimer Research Foundation (www.stopalzheimer.be), roughly 10% of people with dementia are diagnosed with an early onset form of the illness.

Most of the information given in this brochure does not relate to the person's age at diagnosis. The observations are therefore valid for all types of dementia, including early onset dementia.

However, the age of people with early onset dementia does mean that their issues are rather different. In many instances, these people are still working and are fully active members of society, with adolescent children or children studying. They may still have a mortgage to pay. The appearance of dementia turns everyday life for the whole family upside down and brings with it significant financial consequences. Moreover, it often happens that the situation gets worse, both at work and at home, well before a diagnosis is made, with problems of concentration, memory and behaviour. It often takes considerably longer for a correct diagnosis of early onset dementia to be made than is the case of dementia among elderly people.

Happily, in recent years, this problem of early onset dementia has led to more attention being given to it, in research (early onset dementia is often associated with heredity, but knowledge about this is still relatively limited), in the healthcare sector and in regulation. Thus, some regions make provisions and other initiatives specifically focused on care for those with early onset dementia, at home or in an institution. Others launch, as in the Netherlands, 'buddy' operations, whereby a volunteer spends half a day each week, over the long term, with someone who has early onset dementia, in order to build a bond with this person, whilst also doing some form of social activity (sport, handicrafts etc.). The partners and (young) children are not forgotten either: their particular needs in dealing with dementia in a member of the family are also taken into consideration.

www.jongdementie.info is a website (in Dutch) specifically dealing with early onset dementia.

USEFUL ADDRESSES AND WEBLINKS IN WALLONIA AND FRENCH-SPEAKING COMMUNES

PATIENT ASSOCIATIONS

Alzheimer Belgique
40 rue Montoyer, 1000 Bruxelles
Tel. 02-428 28 10
secretariat@alzheimerbelgique.be
www.alzheimerbelgique.be

La Ligue Alzheimer
Rue Walthère Jamar 231/1, 4430 Ans | Tel. 04-229 58 10
A single toll-free number is available in
all 3 national languages: 0800 15 225
www.alzheimer.be

FOR PSYCHOLOGIAL AND RELATIONSHIP DIFFICULTIES

Ecoute Seniors

A service provided by Infor-Homes Bruxelles, Ecoute Seniors offers personalised listening and support. Together with you, Ecoute Seniors can foresee ways of improving your well-being and can, if necessary, find professional support to help you.

59 Boulevard Anspach, 1000 Brussels | Tel. 02-223 13 43
Mondays and Wednesdays from 12h30 to 16h00, Fridays from 9h00 to 12h30
ecouteseniors@inforhomesasbl.be

Senior Médiation

An Infor-Homes initiative that encourages dialogue between the person who is ill and his/her family when they are in conflict (or wish to prevent this), with the help of an impartial mediator who is bound by professional secrecy. The aim is to reach a lasting agreement that is acceptable to everyone involved. All of the protagonists must agree to take part.

c/o Infor-Homes Bruxelles, 59 Boulevard Anspach, 1000 Brussels
inforhomes@misc.irisnet.be
www.inforhomesasbl.be/fr/senior-mediation

Respect Senior
The Walloon agency that fights abuse of the elderly.
It has branches across Wallonia
1 Square Arthur Masson, Bte 2, 5000 Namur
Tel. 0800-30 330, from Monday to Friday, 9h00 to 17h00
contact@respectseniors.be
www.respectseniors.be
To see branches across Wallonia:
www.respectseniors.be/structure/les-antennes-respect-seniors

TO HELP YOU CHOOSE A CARE HOME OR OTHER PLACE TO LIVE

Infor-Homes Bruxelles *is an independent and pluralist association that provides personalised advice about choosing a care home. It visits care homes in the Brussels-Capital Region and meets people from the inspection services. Infor-Homes also offers a mediation service to initiate or restore dialogue in relationships between an elderly person and his/her family. Consultations are by appointment only.*

Infor-Homes Bruxelles
59 Boulevard Anspach, 1000 Brussels
inforhomes@misc.irisnet.be
www.inforhomesasbl.be

Senoah asbl (formerly Infor-Homes Wallonie)
22 Avenue Cardinal Mercier, 5000 Namur
Tel. 081-22 85 98, from Monday to Friday, 8h30 to 17h

Le Bien Vieillir
This association helps people when they change where they live and helps them to search for and access information.
2 bis Rue Lucien Namêche, 5000 Namur
Tel. 081-65 87 00, from Monday to Friday, 9h00 to 16h00
lebienvieillir@skynet.be
www.lebienvieillir.be

OTHER FRENCH-LANGUAGE INFORMATION WEBSITES

www.lebienveillir.be
www.notaire.be
www.alz.ch
www.alzheimer.ca/en
www.alzheimer-schweiz.ch.fr
www.handicap.fgov.be

OTHER USEFUL ADDRESSES

ADMD - Association pour le Droit de Mourir dans la Dignité asbl
144 Avenue Eugène Plasky bte 3, 1030 Brussels | Tel. 02-502 04 85
info@admd.be | **www.admd.be**

Baluchon Alzheimer Belgique asbl
1326 chaussée de Wavre, 1160 Bruxelles | Tel. 02-673 75 00
info@baluchon-alzheimer.be | **www.baluchon-alzheimer.be**

Bureau de tarification du Fonds commun de Garantie automobile
Tel. 02-287 18 11, from 9h00 to 12h00
bt-tb@fcgb-bgwf.be | www.bt-tb.be/auto

CARA - Centre d'Aptitude à la Conduite et d'Adaptation des Véhicules
Institut Belge pour la Sécurité Routière
1405 Chaussée de Haecht, 1130 Brussels | Tel. 02-244 15 52
cara@ibsr.be
www.vias.be/fr/particuliers/cara/

Fednot (Fédération Royale du Notariat Belge - Royal Federation of Belgian Notaries)
30-34 Rue de la Montagne, 1000 Brussels | Tel. 02-505 0811
www.notaire.be

Fédération wallonne des soins palliatifs – FWSP
175 Rue des Brasseurs, 5000 Namur | Tel. 081-22 68 37
federation@fwsp.be | **www.soinspalliatifs.be**

King Baudouin Foundation – Fondation Roi Baudouin
21 Rue Brederodestraat, 1000 Brussels
Tel. 02-511 18 40
www.kbs-frb.be/en

Several free publications about dementia are available free of charge, including:

- *Guide pratique pour les administrateurs familiaux – Fondation Roi Baudouin – Notaire.be, (2018)*
- *Zoom : Dementia. Balance between protection and autonomy (2018).*
- *I'm still the same person – Ten years' working together to create a dementia-friendly society (2018)*

These can be downloaded from the KBF website www.kbs-frb.be, or ordered free of charge as a printed version from the Foundation's Contact Centre | Tel. 070-233 728 | *publi@kbs-frb.be*

BRUSANO
A pluralist association for palliative care in the Brussels-Capital Region
15 Rue de l'Association, 1000 Brussels
Tel. 02.880 29 80, Monday to Friday 9h00 to 17h00
info@brusano.brussels | **www.brusano.brussels**

La Plateforme Alzheimer Luxembourg
Villa Servais, 41 Avenue d'Houffalize, 6800 Libramont
plateforme.alzheimer@province.luxembourg.be
www.plateforme-alzheimer.be

UNIA
An independent public service that fights discrimination and promotes equal opportunity
138 Rue Royale, 1000 Brussels | Tel. 02-212 30 00
info@unia.be | **www.unia.be/fr**

SUPPORT FOR CARERS

Aidants Proches asbl
This association has created an emergency help service for family carers, as well as a service for the person cared for, which enables the identification in emergency cases of a person needing daily help.
4 Route de Louvain-la-Neuve Bte 2, 5001 Belgrade
Tel. 24/7 helpline: 081-30 30 32
www.aidants-proches.be

Le réseau SAM pour les aidants proches
Boulevard De Smet de Naeyer 570, 1020 Brussels
Tel. 24/7 helpline: 02-474 02 44
info@reseau-sam.be | **www.reseau-sam.be/fr**

USEFUL ADDRESSES AND WEBLINKS IN FLANDERS AND DUTCH-SPEAKING COMMUNES

INFORMATION ABOUT PATIENT SERVICES AND DEMENTIA EXPERT CENTRES

Alzheimer Liga Vlaanderen
Toll-free phone number: 0800-15 225
secretariat@alzheimerliga.be | **www.alzheimerliga.be**

Expertisecentra Dementie Vlaanderen
Tel. 03-609 56 14
info@dementie.be | **www.dementie.be**

1712 – Helpline for all forms of abuse
Tel. 1712 | **www.1712.be**

INFORMATION ABOUT DEMENTIA

www.dementie.be (with a chatroom)
www.omgaanmetdementie.be
www.jongdementie.info (early onset dementia)
www.onthoumens.be

INFORMATION ABOUT CARE HOMES

A brochure giving information about care homes for those with dementia when home care is no longer possible.

Download from: www.dementie.be/wp-content/uploads/sites/13/2019/12/D24-Brochure-Wat-als-thuiswonen-niet-meer-mogelijk-is.pdf

Vlaams Agentschap Zorg en Gezondheid
(Flemish Agency for Care and Health)
info@zorg-en-gezondheid.be | **www.zorg-en-gozondheid.be**

Zorgnet-Icuro
post@zorgneticuro.be | **www.zorgneticuro.be**

VVSG, Vereniging Vlaamse Steden en Gemeenten vzw
(Flemish association of towns and communes)
info@vvsg.be | **www.vvsg.be**

Vzw Home info
info@home-info.be | **www.home-info.be**

VLOZO – Vlaams Onafhankelijk Zorgnetwerk
info@vlozo.be | **www.vlozo.be**

HOME SUPPORT DURING A CARER'S RESPITE LEAVE

Baluchon Alzheimer België
info@baluchon-alzheimer.be | **www.baluchon-alzheimer.be**

SERVICES FOR THOSE WITH DEMENTIA AND THEIR CARERS

Steunpunt Mantelzorg vzw
info@steunpuntmantelzorg.be | **www.steunpuntmantelzorg.be**

Samana CM
info@samana.be | **www.samana.be**

Ons Zorgnetwork vzw
onszorgnetwork@samenferm.be | **www.s-plusvzw.be/s-plus-mantelzorg**

Liever Thuis LM
lieverthuis@lm.be | **www.lieverthuislm.be**

S-Plus Mantelzorg
mantelzorg@plusvzw.be | **www.s-plusvzw.be/mantelzorg**

OTHER USEFUL ADDRESSES

Federatie Palliatieve Zorg Vlaanderen vzw (Flemish palliative care association)
info@palliatievezorgvlaanderen.be | **www.palliatievezorgvlaanderen.be**

Vlaamse Ouderenraad vzw (Flemish council for the elderly)
info@vlaamseouderenraad.be
www.vlaamse-ouderenraad.be

FSB – Federatie van de Brusselse Diensten voor Thuiszorg (Brussels homecare services federation)
info@fsb-aideadomicile.be
Website: www.fsb-aideadomicile.be/nl/

King Baudouin Foundation – Koning Boudewijnstichting
Other free publications about dementia are available, including:

- *Praktische gids voor familiale bewindvoerders (A practical guide for family trustees) King Baudouin Foundation – Notaris.be (2018)*
- *Zoom : Dementia. Balance between protection and autonomy (2018).*
- *I'm still the same person – Ten years' working together to create a dementia-friendly society (2018)*

These can be downloaded from the website www.kbs-frb.be or obtained free of charge via the Foundation's contact centre: 02-500 54 55, or publi@kbs-frb.be

Koninklijke Federatie van het Belgisch Notariaat
(Royal Federation of Belgian Notaires)
www.notaris.be

LevensEinde Informatieforum – LEIF (End of life information)
info@leif.be | **www.leif.be**

Recht op Waardig Sterven – RWS (End of life legislation)
info@rws.be | **www.leif.be**

Tariferingsbureau van het
Belgisch gemeenschappelijk waarborgfonds
bt-tb@fcgb-bgwf.be | **www.fcgb-bgwf.be**

CARA – Centrum voor Rijgeschiktheid en Voertuigaanpassing
cara@vias.be | **www.vias.be/nl/particulieren/cara**

UNIA
An independent public service that fights discrimination and promotes equal opportunity
138 Rue Royale, 1000 Brussels | Tel. 02-212 30 00
info@unia.be | **www.unia.be**

Woonzorglijn (meldpunt voor vragen en klachten over woonzorgcentra en assistentiwoningen – helpline for assistance in finding residential and other care centres)
Tel. 078-15 25 25
woonzorglijn@zorg-en-gezondheid.be | **www.woonzorglijn.be**

COLOPHON

DEMENTIA AND HOW TO DEAL WITH IT

Deze publicatie bestaat ook in het Nederlands onder de titel :

DEMENTIE, HOE ERMEE OMGAAN?

Cette publication est également disponible en français sous le titre:

LA MALADIE D'ALZHEIMER...QUE FAIRE ?

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Working together for a better society

notaire.be notaris.be

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